Catalyst WebQ - Preview

Title: Why patients decline genomic sequencing studies: Experiences from the CSER consortium

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CSER GC Decliner Survey- Part A

Question 1.

What is your patient population? (choose all that apply)
Required.

Prenatal

Pediatric

Adult

Question 2.

What is/are the clinical indication(s) for your patient population?
Required. [free text]

Question 3.

Does genetic counseling take place before the participant is initially approached about the research project?
Required.

Always

Never

Sometimes. If sometimes, in what context(s)

Question 4.

Is the consent form provided in advance of the initial information session? (choose all that apply)
Required.

Always

Never

Sometimes. If sometimes, in what context(s)

Question 5.

Is the consent form provided in advance of the informed consent session? (choose all that apply)
Required.

Always

Never

Sometimes. If sometimes, in what context(s)

Question 6.
Who initially approaches the participants?
Required. [free text]

Question 7.
How is the initial approach made? (check all that apply)
Required.

Over the phone

By mail

In person. If in person, is this in a clinical setting? Yes or No. If yes, please describe the clinical context.

Question 8.
What initial information about the study is provided?
Required. [free text]

Question 9.
Who provides this initial study information?
Required. [free text]

Question 10.
Who conducts the formal informed consent conversation?
Required. [free text]

Question 11.
What is the average length of time of your informed consent conversations? Please include whether this number is an estimate or based on data.
Required. [free text]

Question 12.
What is the range of time of your informed consent conversations? Please include whether this number is an estimate or based on data.
Required. [free text]

Question 13.
Who is providing informed consent? (check all that apply)
Required.

Proband only

Both parents (required)

Both parents (if available)

Mother only

Father only

Assent

Other:

Question 14.
*Active decliner = decline after responding to a phone call or mail request to participate OR decline during the informed consent conversation
How is active decline* received? (choose all that apply)
Required.

Over the phone

By mail

In person

Question 15.
When is active decline* received? (choose all that apply)
Required.

Before informed consent conversation

During informed consent conversation

After informed consent conversation, prior to signing consent

Question 16.
What data did you collect for passive decliners? (choose all that apply)
Required.

Rate of passive decline

Rationale for passive decline

Did not collect passive decline data

Question 17.
Please include any information about the passive decline process you would like to share. [free text]

Question 18.
Do you have any interesting quotes that could potentially be included in a final manuscript?
Required. [free text]

Question 19.
What educational resources are provided?
Required. [free text]

Question 20.
Are these educational resources provided (choose all that apply)
Required.

During the initial approach

After the initial approach/before the informed consent conversation

During the informed consent conversation

After the informed consent conversation

Question 21.
Did your IRB deem your study more than minimal risk?
Required.

Yes

No

Question 22.
Please include any comments you would like to share about your IRB designation. [free text]

Question 23.
How many pages is your study consent form currently?
Required. [free text]

Question 24.
Has the number of pages changed during the course of your study?
Required.

Yes

No

Question 25.
If the length of the consent form has changed, what content was modified? [free text]

Question 26.
If the length of the consent form has changed, what proportion of participants were approached/consented prior to the change? [free text]

Question 27.
Please share any final notes or comments. [free text]

CSER GC Decliner Survey- Part B

***Decliner = decline after responding to a phone call or mail request to participate OR decline during the informed consent**

Please fill in the table below.

Enrolled probands	Total number of decliners	Rate of decline

Please list the categories of reasons for decline and how many potential participants cited this reason.

Category	Total number of decliners
(can add additional categories if needed)	

Follow up questions (highlight answers)

1. **Can more than one category be chosen for each participant?**
   - **a.** Yes
   - **b.** No
2. **What were these categories?**
   - a. Multiple choice, defined **before** the study
   - b. Multiple choice, defined **during** the study
   - c. Coded from free text responses